ICC MEETING MINUTES SEPT 12 & 13, 2018

INTRODUCTIONS

Sarah Carlson Matt Nelson Meredith Quinn Carol Brakel Tanya Canerot Jodi Hulm Chris Pieske Moe Schroeder Rebecca Eberhardt Mary Haugen Val Bakken

STAFF

Jackie Adusumilli Colette Perkins

Guests

Brenda Boehler Tami Conrad Amanda Carlson

TOPIC: AGENDA

2 additions - Consensus Council, Children's Behavioral Task Force and NDCPD Dual Sensory Project.

TOPIC: MEMBERSHIP

Members are waiting on appointments.

Chris talked with Dave S. an attorney in his office and all boards are having problems getting members reappointed. Terms have expired, and members have not yet been reappointed/replaced. I think you can continue voting until you are reappointed.

Sarah has contacted the Governor's Office also.

TOPIC: FAMILY STORY

Kyle Mallard parent of Skip E. and turned 3 on Sept 7 and graduated out of early intervention and started in BECEP. Skip was born at $37 \frac{1}{2}$ weeks. At 2 months,

failure to thrive, son couldn't nurse, couldn't lash, didn't respond to light or visual stimuli and we knew something was up and had no idea where to go. Skip was hospitalized and had a hernia, couple of holes in his heart and went to children's Sanford over Christmas 2015 and contracted RSV and put on an eng tube, etc. Spent 10 days in the hospital. They were never told about any services or resources for Skip. Couldn't perform surgery because he is so sick and be on tube for a couple of months. Gave an optional consultation with a nutritionist in Fargo. She asked if we would be applying for core services and they didn't know what she was talking about. Contacted the county social worker. If there is a way to encourage providers to contact parents/children about services in a more dynamic way, it would be good. At 4 months approved for early intervention and set up with Medicaid. Floored with the quality of services Skip has received. We want to advocate for our kids and take advantage of the programs available. Make it more seamless, transparent and accessible to our kids.

Jill stated they talk to providers every year regarding children being served by the system. Dr. refers out patient, they are calling about a referral.

TOPIC: FAMILY SURVEY TECHNICAL ASSISTANCE

Kyle received a survey and completed and returned. We want to talk about the family survey and family engagement and information going out to the families and stakeholders.

We will be looking at the data, response rate, looking at the representative groups and ideas to improve on, how to share information we are gathering through the family survey and how to let public let know the importance of the data, follow through with families and discuss ways to use the family survey and data and improve actions and surveys.

Video:

Ideas on how to approach the questions and how to help staff.

Sharon Walsh - key team is the family outcome team. Part C Indicator 4 is data summary.

Performance data - don't use the data, then you really don't do anything. Want good high-quality data that represents families and then use it for improvement.

Current year Trends over time

State approaches

Surveys used
Family populations surveyed
Dissemination and return methodology

Data Quality
Response rates
Representativeness

Did we help families improve their ability to know rights, effectively communicate child needs, and help child develop and learn

What data are included: FFY 2016 numbers
Some coding
National webinar

FFY 2016 National Performance

4A - 90%

4b = 91%

4C - 92%

Look and see how our data compares to this.

When child participates and have access to broader outcomes they are better off. There was discussion

about linking data and families; unique identifiers; possible to match data with technical assistance and deal with confidentiality;

Share, link, harvest, and display data.

State longitudinal data system - South Dakota.

Designed to link data up through post-secondary. Links with community college, higher ed, and some focus on early childhood. Sharon has state examples that she can share. UT has good examples.

Dept of Public Instruction information goes into sleds and all agencies feed into it but can't get information back from it. DHS information is not Part C data, child care assistance or economic assistance. 636 were referred from Part C to Part B; and 442 found eligible, and 186 not found eligible.

Collect high quality data:

Using data and linking with other data sets to improve your programs and funders what to know the value of our programs.

How collect:

Samples or look at all families.

Analysis each state's APR data.

30 states survey all families in the program.

19 states have to have approved sampling

Census vs sampling

ND uses census.

We do some subgroups - around IFSP meetings.

Survey timing:

Point in time - 22 states

At IFSP - 5 states

Exit program - 9 states

Dissemination & return:

Dissemination methodologies - 56 states

17 mail

13 in person by ser coordinators

10 multiple methods

2 other

14 not reported

24 states there is an online option - what about duplicates? You can code for that.

Return methodologies:
26 multiple ways
9 mailed
1 in person
2 other
Not reported/unclear

Survey response rates FFY 2015
43 states reported a response rate
Response rates ranged from 99.2% to 100%
Mean response rate - 33%
Median response rate 34%

Response Rates and survey methods
In person distribution 53% - 13 states
Multiple 39% - 10 states
Mailed only distribution - 21%
Average response rates - 17 states

Multiple return methods - average response rate 35% -= 26 states

Mailed return - average response rate 25% - 9 states

Data quality
Representativeness of family data
Were data representative of states population?
Yes - 47 states
No - 9 states

Variables analyzed by states:

Race/ethnicity
Geographic variables (district, county, region)
Child's age (at item of survey, at referral
Others: disability/eligibility categories, length of time in services, income, primary language

Sarah read some historical information:
How do we know everyone receives one?
What is the methodology in getting them back - is there
a self-addressed envelope? Hand delivered - do in the
moment, fill out and hand back -- add these details in.

In person contact has made a difference for some years.

Jackie reviewed ND Family Surveys Returned vs. Children Eligible FFY 14/16.

Lending success from one region to another that is not as successful would be good to do.

Council recommended that this be shared in reports and regions would appreciate input also.

Carol and Jill stated that they really want this data. In the reports, regions get the survey information but not the return information. How many professionals are supporting to get the survey information in - Region G. Can we see urban vs rural - need an identifier; list county. Make sure every family receives a survey - in person has to be checks and balances; how to make sure you capture this; this year it went out to every family.

Moe said there are families in Region 5 that should have gotten a survey that haven't gotten a survey. Carol tracks in her region who gets a survey.

ND family surveys retuned by race state level FFY 2014/2016.

This is state data.

Doesn't show language spoken in the home.

This year we provided a Spanish version.

In-take identifies language.

Other states use language line - someone interviews the family.

Region IV uses the language line at in-take.

Requesting accommodation - automatically do.

We need to have regions telling us what they need for speaking/reading languages.

ND family survey response rate by region for FFY 13/16. Does this represent what families in ND are feeling and if influenced by delivery method, representative group.

Moe, Eric, Meredith, Beth, and Carol will meet and bring a recommendation to the full Council in January for review.

3 steps:

Decision if item 1 or item 2 are a priority. Intended use of data and get it out, or who we are serving and how to increase response.

Focus on #1

Need #2 to be in place before we can implement #1. How we deliver and collect, comes after making sure it is meaningful.

Focus on representative response - how to get a better return rate from the minority.

Education on the survey itself - parents and providers.

Need to help the program survive. Need to sell these numbers that we have to the legislators to get more money.

Online vs paper - last year and report this and that, etc. Survey - opportunity of your services and what they are providing.

Use the data we have to go forward and do training. Info graph in the bulletin board, peds wing, NICU, etc. another for decision makers.

In the letter, list the link for the online version and let families know they have the option. The subcommittee makes a recommendation to the ICC in January, and the ICC makes recommendations to the State.

TOPIC: CONCENSUS COUNCIL

Children's Behavioral Task Force was started due to Legislation. Task force includes members of Health Dept, DHS, DPI, P&A, Corrections, and Indian Affairs. Working on specifically the area of behavioral health for children. Asked of the ICC, if someone could attend their next meeting on Fri, Sept 21, at 10:25 for discussion on collaborating with them on children's lives and/or impactful for the children we serve.

Moe will do if she gets reimbursed travel and if not, Sarah will send a copy to Chris.

NDCPD is working on a grant to assume the dual sensory project. They want to assume these services and improve on these services. They would like the ICC to write a letter of support for this grant. Sarah invited Cathy Harstad to come and talk to the ICC. Does school for blind and school for deaf have an intention of writing a grant proposal for this and having more expertise than an entity that is beginning a new project? Sarah said that both have offered their support for NDCPD to write this grant.

Val added support but not a lot of support for families, focus for grant money to be utilized for

family specific activities, resources or training. Carol gave support but have them provide joint training on dual sensory for providers and DDPMs, encourage them to provide training. A motion was made by Carol Brakel and seconded by Shannon Grave that NDCPD connect with DHS for a letter of support for their dual sensory project. Motion carried.

TOPIC: INTEMIRIM HEALTH SERVICES COMMITTEE

Chris messaged Becky Matthews, but she had to leave. Val was there are a small section - Presented by legislative assembly - money in common school's trust fund used to support school and used as investments. Discussed funds utilized to support schools.

Common schools trust fund - not used and what if school was providing early intervention services and stumped him and lists look into that.

Maggie provided child support issue - feedback from CMS it can be changed to \$50, \$100 the amount of recipient liability - if child is receiving income.

1st partial month - family has Medicaid and referred to early intervention can access and screen right away. May be able to change through policy to capture MA dollars. Other entities cannot pay the recipient liability.

Jordan nurse family partnership services provided information. Asked how they intersect with early intervention. Roxane submitted something on friends of Part C and Sen. Lee distributed and asked members to read but it wasn't discussed.

This will be discussed with the IDEA group on Thurs.

TOPIC: ATTORNEY GENERAL - ICC REPRESENTATION

No update.

Invited our friends to join us for a meeting. Table and talk about in Dec. Sarah sent the questions from July.

TOPIC: ELECTIONS

Sarah hasn't heard from Julie yet.

Nominated and accepted the Chair - Sarah C. Vice chair - 3 nominations - Val Bakken, Becky Eberhardt, and Moe Schroeder. Val and Becky both withdrew.

Becky done 8/31 Tammy 8/31 - retiring Dave, Jill, Val, Holly, Sarah - need appointment Steve - not looking for reappointment

Have done elections via survey monkey.

A motion was made by Chris Pieske and seconded by Matt Nelson to move that the current chair and vice chair remain in office until the membership status of the chair nominee is clarified by the Governors' office and hold an electronic election.

The motion was amended by Val Bakken and seconded by Chris Pieske to amend the motion that Sarah continue in the role as chair while waiting reappointment and we have a formal count of Moe's promotion to vice chair. Vote to amend the motion carried. Motion carried.

TOPIC: REVIEW STANDARD OPERATING PROCEDURES - PARENT COMPENSATION

Birth to 5 language, parent compensation. Sharon was asked what other states do. Time reimbursement is less frequent.

Sharon said they could do a survey on what other councils do and provide input to the council. Stipend is not the same frequency as expenses.

ND pays mileage, hotel, and food are being paid.

Stipend has caveats tied to it that are complicated.

Look into example of a provider paying up front for a someone to come to the ICC and then the provider gets reimbursed from the state.

Wait until Sharon gets back to the ICC and then Chris will write a proposal on how to change it.

What does VR reimburse for parent stipend? IDEA does not compensate. Special health services - 3 hrs. is \$75.

For the chair/vice chair is that a different stipend than the rest of the parents on the committee.

ICC chair to IDEA chair - IDEA role is to advise, and Shannon doesn't work days to do this, and send out for comments and email a couple of times and then we are done.

What does DD Council pay? Ask

Sharon - allow virtual participant - if I'm eligible for a stipend and I call in will I get a stipend. If I call in, can I get paid. If you aren't here in the morning, do you get the same stipend amount if you only attend in the afternoon.

The Standard Operating Procedures will be revisited in December.

A motion was made by Chris Pieske and seconded by Val Bakken to change 0 to 5 to be 0 through 2 with Section 3. Motion carried.

Membership:

Have someone show up as a designee and can't vote and they should be contacted.

Excused absence is that ok?

Discretion about future membership may be decided by the ??? - decide as a committee the position should be filled by someone else.

Member removed from chronic nonattendance or chair request the Governor's Office to contact someone about chronic non-attendance.

RSVP is very important to let Jackie know whether you can or can't come.

Anyone can get contacted with 2 no shows.

Add misses 2 consecutive meetings with no contact.

A motion was made by Chris Pieske and seconded by Meredith Quinn to add if continued absence occurs the Executive Committee may vote to instruct chair to contact the Governor's Office to request that the member be removed. Motion carried.

Federal regs from 2011 - has someone reviewed these regs regarding this conversation.

Conflict of interest - Chris suggested adding "conflict shall be determined by the chair".

TOPIC: SET 2019 MEETING DATES

Jan 24, 2019, 9am to 5pm video conferencing March 28, 2019, 9am to 5pm video conferencing June 26/27, 2019, 9am to 5pm in person - IDEA joint meeting

Sept 25 & 26, 2019, announce later - IDEA joint meeting Dec 19, 2019, 9am to 5pm video conferencing Jan 23, 2020, 9am to 5pm video conferencing

TOPIC: COMMITTEE REPORTS

EI Budget Committee

No report. Chris will get something together when he can.

Executive Committee

Reviewed the parking lot tool. Continues to make modifications and reflect the progress that we are making.

EI Services Committee

Barrier of direction of state of this is what we need to do to streamline. Do we want to say this is how we can streamline administrative oversight of Right Track? Coordinators and entities don't feel they can make decision on changes and what are possibilities and need the state input. Missi asked to be added to the committee.

SSIP Committee

Family Survey - Moe is lead

TOPIC: SSIP Update

TOPIC: GENERAL SUPERVISION UPDATE

TOPIIC: LETTERS OF FINDINGS AND LEVEL OF DETERMINATIONS

Levels of Determination were issued in June.

5 programs had meets requirements and 5 programs had needs assistance.

Send out letters to programs based on performance on our indicators where they are at.

Letters of Findings - issue on Indicator 1 - timely initiation of service (7 programs), Indicator 7 - 45-day timelines (5 programs) and Transition 8a, 8b (3 programs), 8c. Number of findings and resolved - they have a year to resolve. Will get a report on the systematic work. Issued letters in all compliance areas.

Transition concerns this year.

Family reason - does the family know the state has reported this as family reason for a delay.

Regional Program Reports and Program Level of Determinations have been placed on the early intervention website.

TOPIC: DD SLOTS REPORT

Waiver year 4/1 to 3/31

Every year of the Waiver period the number of common slots for anyone eligible for waiver increases by 105. 4,982 slots assigned, and we have 508 left How many of the slots are early intervention? How many are infant development and number not on the waiver?

When we run out of common slots we have reserved slots. 190 reserved slots and there are 135 for infant development; plus 5 for Extended Services and 50 for emergency slots.

We would have to have legislative approval to increase the slot numbers and then submit a waiver amendment to CMS.

TOPIC: PART C BUDGET REPORT

We have started using FFY 18 funds in July. Printing costs are up because of printing transition quides and AEPS materials.

Part C, Medicaid, state general funds = quarterly budget insight on the website would give you a total

but the federal of Part C and Medicaid is not broken out. Breakdown the expenditures of Part C by 12 months, 18 months, etc.

Look at timeline of how fast spending the money. Can there be a graph/chart showing how much is being spent from the Part C grant total each month. Got extra money for Part C and did that get spent? Part C is supposed to be the payer of last resort but so is Medicaid.

Projections - we look at what contracts are spending on a quarterly or monthly basis.

What did we spend last July compared to this July? Graph this FFY was spent in 16 months and go back 8 years. Part C funds and the total cost of things - this is how much extra money was needed and over time this is how this has increased or decreased and how many people are being served for that amount

1st partial month is always Part C.

How many pay points specific pay points bill for the number of children enrolled each month? Consults - 2 per 6 month period/4 for year.

IFSP, home visit, consult or evaluation - are the 4 pay points and each having a different dollar amount assigned to them.

Number of consults and number of evals for the last 4 years from providers - this information is in Therap.

IFSP development, IFSP update.

Maybe adding a 5th pay point?

Number of consults billed in 2017 divide by kids, 2016, and 2015.

DD service grant line $-1^{\rm st}$ partial month and pay points and break down by how many kids are served, what are the pay points and break these down and what are the services.

Tina spenddowns are broken down by pay points. Not an unduplicated child count. How many kids and how many expenditures.

Can we separate out the $1^{\rm st}$ partial month - not from what DD has, there is not a separate billing code. Can we separate $1^{\rm st}$ partial month from those that did apply or don't qualify for Medicaid. Can we do quarterly?

Tina can break out billing codes. Division doesn't have access to this information and would to pull in fiscal and Medicaid. A lot of manipulation on 1st partial month will not be easy. 4 pay points — fiscal division can do. Providers what have you billed for 1st partial month. Moe — talked about what you can see what is being paid and from where and will send to Tina.

Council recommends to state what we can accomplish Pay points broken out
Length of time looks going back
Part C funds and number of children served
Look at the high-risk list?

Chris - look at the pay points and review quarterly information on pay points. For step-ons don't know how current they are. Pay points developed - are they accurately reflecting what is currently being done. Billings are more IFSP development and update compared to originally decided. Is the amount per pay point appropriate or should they encapsulate different things or add pay points?

Switched to pay points - here is how much money we have and ask providers how many do you do and this is how the rates were established.

Obtain pay point information from Tina and 1st partial month from providers. Send me what you billed for first partial month (providers) and how many new people (Jackie has); May 2018 and July 2018; providers have for a year.

The Division's report will be direct service break out by 4 pay points, Medicaid, federal, state match for Medicaid, DD Part C.

Can we figure out how much DDPM time costs for service coordination? Tina stated that there would have to be changes. Medicaid eligible and DDPM doing work regarding Medicaid we have one code. We don't ask DDPMs to separate out, they lump it as one number. Not Medicaid and under 3 is a separate code. Create a separate code for kids under 3 and Medicaid and tracking by individual. The Division is working on a DDPM time study in general for overall.

Are pay points enough, too much, do they accurately reflect what you are doing.

Look at pay points and if they meet what you are doing and then pass over to budget committee and if struggling to get what we need then in Dec we can ask the state for assistance in obtaining the information.

Visual from providers on pay points, adding number of kids served May to Nov. State Office pay points in general of the direct service budget. For the Division - Part C, other funding, total cost of program, number of children served, graph federal fiscal year pending last 10 years; early intervention subcommittee - pay point rates and send back to budget committee or back

to council or to request to the state for additional information from providers. FFY 10 = how long does it take to spend the funds - when we were awarded the contract and when did we start spending/how long did it take to spend.

What does the provider contract say when we ask for this information and are providers willing to share this information? Tell providers why you are asking for this information.

Jill sent link to Jackie what providers gathered over a 6 month period and displayed for the members to review. Jan 17 to June 17 and divided what was billed for what families choose Part C and $1^{\rm st}$ partial month. Bill for an eval - any yearly evaluation and helping Part B could be a transition evaluation. Jill have never billed MA for $1^{\rm st}$ partial month.

Kids already on Medicaid is there a way, instead of whole month to Part C, found eligible on this date and start on Medicaid but how would recipient liability impact this also.

TOPIC: NDICC MEMBERSHIP UPDATES

Reached out to Devils Lake and a Minot representative. Addition of a member related to Corrections. If families are receiving these services, are kids less likely to end up in corrections.

Provide support for early intervention services to say support would impact of preventing or potential of impacting kids coming through corrections. This is related to SB 2325.

What about possible policies on safety also that could be provided from them?

This could fill the provider position vacated by Steve.

Seek out before we increase - contact Lisa and ask if someone would be interested.

What about the provider role and any suggestions to seek out? Maybe reach out to Indian Affairs. Lutheran Social Services has a really good parent working for them. Indian Child Welfare Act - they work with families.

TOPIC: PATHFINDER REPORT

Brenda didn't have a lot to report.

Jodi sent her regards and sorry that she could not be here.

Jodi gave some reports to be distributed to members, plus some fliers and getting people involved in the early intervention process. Getting Experienced Parent support across the state, lacking an Experienced Parent in Regions 2, 3, 5 and 6. Actively seeking Experienced Parents.

Getting list together for parents across the state and if you want a copy email Pathfinder. Parent Center is up and running and doing well. Seeing less need for the resources in the Center. If you need anything from the Parent Center, email Pathfinder.

Experienced Parents on staff - 4 - Region 1 - Jocelyn Lynch; Region 4 - Lana Beaton; Region 7 - Katherine Dockter; Region 8 - Sarah Carlson

Lots of new staff and will be seeing a lot of changes.

How many families are receiving those minutes? What is the definition of contact and what is the definition of contact minutes? Contact is direct minutes. New brochures - when are we going to be seeing these? Cannot find a list of Experienced Parents on the Pathfinder website.

Brenda will give these questions to Cassie.

How many families are being served? Because someone is there doesn't mean referrals are happening.

33 families statewide - how many families is this or is it 33 contacts. How many families in each region and how many families is an experienced parent serving in their own region plus statewide? DDPA doesn't know who the Experienced Parent is seeing. Experienced Parent should be invited to EI meetings.

How many hours within the budget are designated to staff time for one on one support? Experienced Parent should be part of the IFSP team. Money coming from Part C to Pathfinder - we need to see support for families and how many families and is it going to family support.

How do we capture uniformity if each region - looks different?

What training is there for Experienced Parents through Pathfinder? Not sure how the training relates to direct support to families. Training on med app and how to complete; what forms are needed for out of state approval travel?

Pathfinder is a standing agenda item. \

Here are the responses Colette received from Pathfinders to the ICC questions:

How many people does the EP program serve?

Our ICC report indicated that we had 118 contacts with families. DHS does not require us to report regionally or by number of families served. The numbers that we report are a summary of the data collected as required by DHS.

Can we break the data down to families being served and Regions?

After looking into this request a bit closer from last ICC meeting, it was found that it would not be in the best interests of the clients to report regionally to retain privacy. Hopefully as the numbers grow in each area we will be able to provide more regional data.

Where are the brochures on EPP?

As stated in the reports, Brochures have been distributed to; NICUs, REAs, Social Services, SPED units, Community Meetings, Booths, Food pantries, and Conferences (SPED Directors and NDMTSS Conference). As we move forward and begin to implement our new Experienced Parents Guidelines, each Experienced parent will also be responsible for distributing and sharing the EPP brochures in their assigned areas. Also stated in the report, The ED and the new Family Support Specialist are revisiting the outreach plan for brochures.

If there is a specific place you would like for there to be more brochures, please email; epp@pathfinder-nd.org

What training do the EP's get?

As stated at the last ICC meeting and in the last report, All Experienced Parents will be receiving the same 10 module webinars based on the building a legacy training created by NICHCY and updated by CPIR. With the new Family Support Specialist, these have been reformatted and the first three modules are currently being recorded.